

Lessons learned from systematic public health follow-up of diagnoses of CJD for surgical risk, in England

Glass R, Checchi M, Sinka K

National Infection Service, Public Health England (PHE)

INTRODUCTION

Around 100 new diagnoses of CJD are made each year in England. An estimated 80% of these patients will have had surgery in the past, some including tissues considered infective for CJD [1]. Public health follow-up aims to identify these surgical incidents and take action to reduce the risk of iatrogenic transmission.

METHODS

Since 2000, the surgical history of patients diagnosed with CJD has been reviewed and the transmission risk of invasive procedures assessed. This considers the type of CJD, type of procedure, the infectivity of the tissues involved and time elapsed between the surgery and point at which CJD is suspected or diagnosed. The follow-up identifies 1) potentially contaminated instruments and 2) exposed surgical contacts. The risk assessment determines whether instruments should be quarantined or destroyed and whether informing exposed surgical contacts is advised.

Between 2000 and 2013 advice on assessment and management of surgical incidents was provided on a case by case basis by the CJD Incidents Panel (CJDIP). During this period, a number of precedents were established that enabled a consistent approach to incident management to be developed. This was recorded in a framework document. Risk assessments underpinning the Panel's advice were reviewed when new evidence became available. For example, when anterior eye tissues were reclassified in two stages to medium-low and then lower infectivity tissues in 2006 and 2009 [2].

In addition, formal communications to the health service have encouraged complete reporting of suspected diagnoses of CJD to the national surveillance system and for hospitals to have systems in place to enable the tracing of surgical instrument sets to patients on whom they have been used (box 1).

From 2013, the CJDIP was dissolved and incident management was devolved to local teams. To support this public health guidance was produced, following the precedents that had been established, and the CJD module in PHE's national case and outbreak management system (HPZone) was updated to reflect the new arrangement. Meanwhile, communication between the national surveillance system and local public health teams about new diagnoses to facilitate public health follow-up was simplified and strengthened.

We used the detailed data collected by the CJDIP for each reported incident before 2013 and reports from HPZone from 2013 to take stock of 16 years of public health follow-up for CJD surgical incidents.

● CJD Incidents Panel (2000 to 2013)

- Assessed and advised on individual incidents to reduce risk of transmission
- Documented risk assessments, decisions and precedents
- Created a framework for incident management

● Referral of unusual neurological cases to national surveillance system [3,4]

● Systems for tracking and tracing surgical instruments to patients [5]

● Standard guidance for risk assessment & management of CJD incidents [6]

Box 1. National measures that improved reporting, follow-up & management of CJD surgical incidents in England.

RESULTS

Between 2000 and 2013, 321 reports of surgery following clinical suspicion or diagnosis of CJD in England, were reviewed by the CJDIP, approximately 30% of CJD diagnoses during the period. Figure 1 shows the key elements considered during the risk assessment of these incidents. Most reports (66%) concerned patients with a diagnosis of sporadic CJD followed by variant CJD (12%) and genetic CJD (6%). A CJD diagnosis was ruled out or considered unlikely in 12% of reports.

Over 900 surgical procedures were documented for these incidents. The median number of surgical procedures per patient was two (range 1 to 17) almost all of which involved low risk tissues for CJD infectivity. In 18 instances surgery involved potentially infective tissues and traceable patients, who were notified. Twelve of these incidents, concerned cataract operations which were later reclassified as low risk. A further 18 incidents, might have led to patient notifications, but lack

of instrument traceability meant a detailed risk assessment could not be done, and exposed patients could not be identified with certainty. Most (88%) of untraceable records were from 2003 or earlier.

From 2013 to 2016, after the dissolution of the CJDIP, 419 records relating to CJD case management were logged on HPZone, 332 of these were in relation probable or confirmed CJD, aligning to 88% of CJD diagnoses during the period. Over 90% of these diagnoses were recorded as sporadic CJD, reflecting both the decline in variant CJD by this time and the continuing gradual rise in sporadic CJD diagnoses. The median time from logging to closing the public health investigation was 1.7 months. Since 2013, three surgical incidents have led to notification of surgical contacts.

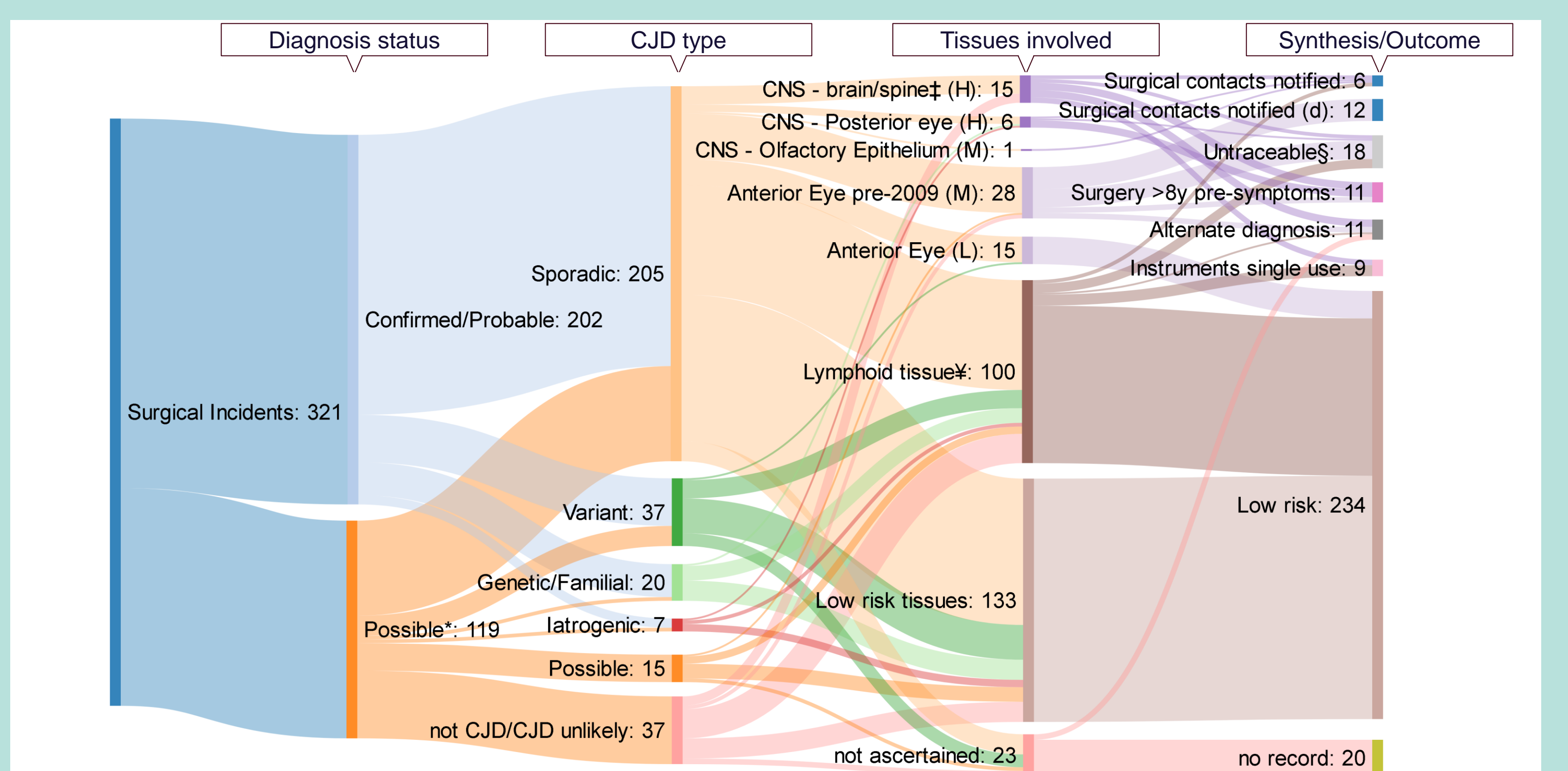


Figure 1. Elements considered during the CJDIP risk assessment of surgical incidents, 2000-2013. England.

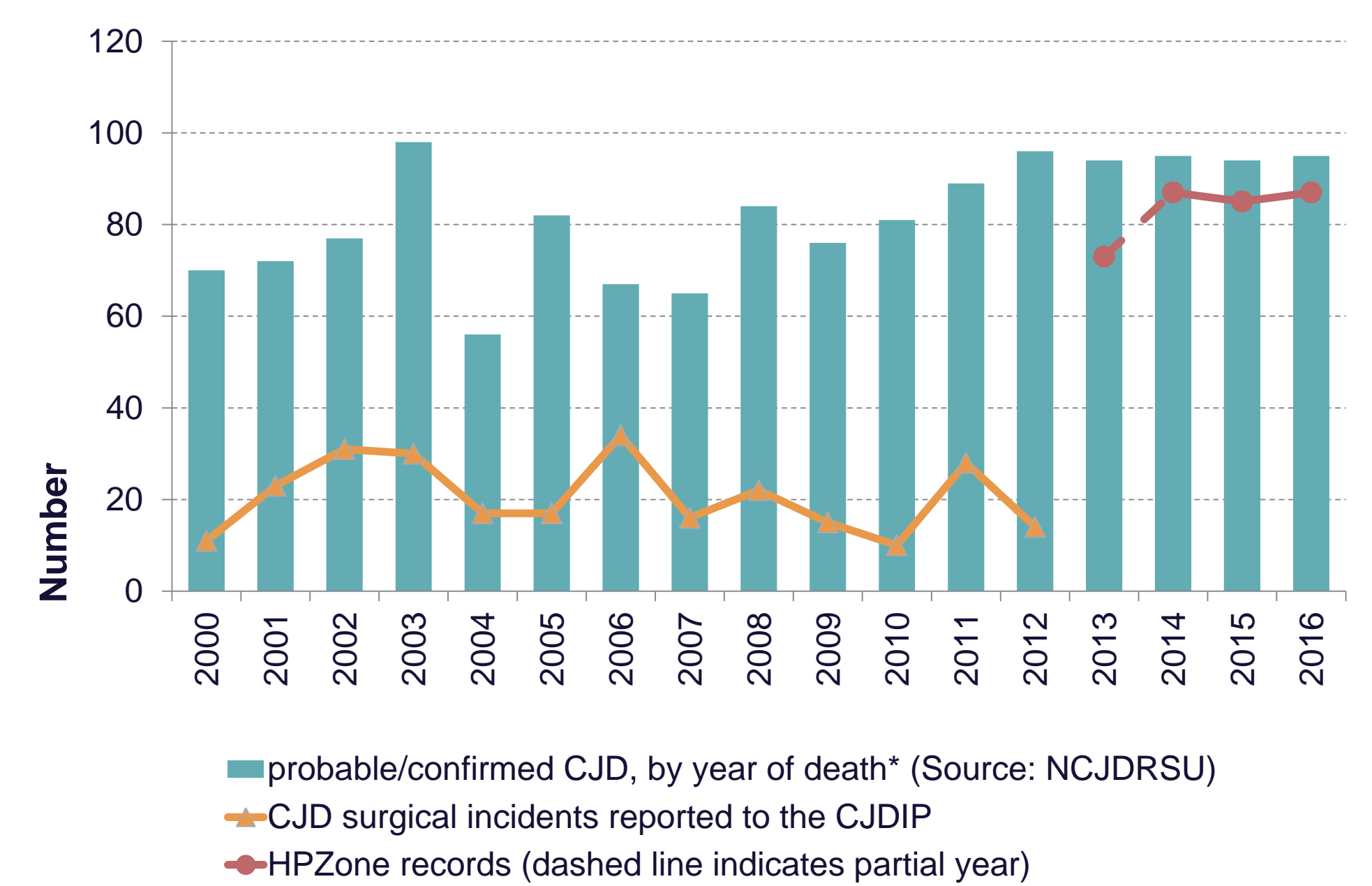


Figure 2. Number of probable/definite CJD diagnoses – 1) reported* 2) investigated by the CJDIP 3) recorded on HPZone by year. England.

DISCUSSION

The majority of surgical histories investigated relate to a diagnosis of sporadic CJD. Previous surgery is common among these patients, including very recent surgery in some cases. The frequency and type of surgery are typical for the age group [1]. Most procedures involve low infectivity/low risk tissues.

The occurrence of higher risk surgical incidents has been and remains infrequent. The individual circumstances surrounding each incident of this type are unique and can be complex. These investigations can take many months to complete. Several instrument sets may have been involved and where the surgery has taken place several years ago, records have sometimes been unreliable or kept as paper files, making the searching extremely laborious. However, establishing the details accurately is essential before informing individuals that they may have been exposed to a risk of CJD transmission.

Improvements in record keeping, instrument tracking and tracing, and communications between the surveillance system and local public health teams all assist the process of public health follow-up to investigate surgical histories of patients diagnosed with CJD.

In parallel the development and maintenance of infection prevention and control guidance, single use instruments where appropriate and improved standards for cleaning and decontamination of re-usable instruments aim to minimise the risks of transmission of CJD in healthcare settings.

Long-term follow-up of surgical contacts since 2000 has not identified any associated development of CJD to date.

CONCLUSIONS

- Systematic follow-up of new CJD diagnoses to identify past surgical procedures remains a cornerstone of the public health action to reduce the risk of healthcare related transmission of CJD.
- Management of surgical incidents has developed alongside changes in decontamination practice, infection control and surgical instrument traceability.

ACKNOWLEDGEMENTS

Figure 1 was created using SankeyMATIC

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